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DIFFICULTIES IN THE FACE OF THE DIAGNOSIS, REPORT OF PATIENTS WITH THE HANSEN'S BACILLUS

DIFICULDADES FRENTE AO DIAGNÓSTICO, RELATO DE PORTADORES DO BACILO DE HANSEN

DIFICULTADES DELANTE DEL DIAGNÓSTICO, TESTIMONIO DE LOS PORTADORES DEL BACILO DE HANSEN

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ABSTRACT

Objective: to analyze possible difficulties faced by leprosy patients to confirm the clinical diagnosis. **Method:** it is a descriptive and exploratory study, with qualitative approach, conducted in three Basic Health Units in Mossoró/RN. The sample was composed of 17 leprosy patients. A form to collect data was used, and they were analyzed through the technique of Content Analysis. The research project was approved by the Research Ethics Committee, CAAE: 12254113.3.0000.5179. **Results:** the solvability in the secondary and/or tertiary care was noticeable. The time spent from the suspicion to the diagnosis, according to reports of patients, is still slow. Such diagnosis is confounded with various diagnoses for other diseases, thereby entailing risk to patients and notifying parties. **Conclusion:** we observed the difficulty and the lack of sensitivity on the part of some professionals in the primary care, authoritarian and ineffective behavior, typical of the hegemonic model, which does not contribute and, even, keeps the patient out of the care actions. **Descriptors:** Leprosy; Diagnosis; Nursing.

RESUMO

Objetivo: analisar possíveis dificuldades encontradas pelos doentes com hanseníase para confirmação do diagnóstico clínico. **Método:** estudo descritivo e exploratório, com abordagem qualitativa, realizado em três Unidades Básicas de Saúde em Mossoró/RN. A amostra foi composta por 17 pacientes de hanseníase. Foi utilizado um formulário para coleta de dados, os quais foram analisados pela técnica de Análise de Conteúdo. O projeto de pesquisa foi aprovado pelo Comitê de Ética em Pesquisa, CAAE: 12254113.3.0000.5179. **Resultados:** foi perceptível a resolutividade na atenção secundária e/ou terciária. O tempo gasto a partir da suspeita até o diagnóstico, de acordo com relatos dos pacientes, ainda é lento. Tal diagnóstico confunde-se com vários diagnósticos para outras doenças, implicando em risco ao paciente e aos comunicantes. **Conclusão:** observou-se a dificuldade e falta de sensibilidade por parte de alguns profissionais na atenção primária, comportamento autoritário e ineficaz, característico do modelo hegemônico, que não contribui e, até mesmo, afasta o paciente do cuidado. **Descritores:** Hanseníase; Diagnóstico; Enfermagem.

RESUMEN

Objetivo: analizar las posibles dificultades encontradas por los enfermos que sufren de lepra para la confirmación del clínico. **Método:** estudio descriptivo y exploratorio, con enfoque cualitativo, desarrollado en tres Unidades Básicas de Salud en Mossoró/RN. La muestra fue compuesta por 17 pacientes de lepra. Se utilizó un formulario para recopilar datos, los cuales fueron analizados por la técnica de Análisis de Contenido. El proyecto de investigación fue aprobado por el Comité de Ética en Investigación, CAAE: 12254113.3.0000.5179. **Resultados:** la resolutividad en la atención secundaria y/o terciaria fue perceptible. El tiempo gastado entre la sospecha y el diagnóstico, de acuerdo con testimonios de los pacientes, sigue siendo lento. Ese diagnóstico es confundido con diversos diagnósticos para otras enfermedades, lo que resulta en el riesgo para el paciente y las partes notificantes. **Conclusión:** se ha observado la dificultad y la falta de sensibilidad por parte de algunos profesionales en la atención primaria, conducta autoritaria y efectiva, característica del modelo hegemónico, que no contribuye y, incluso, mantiene el paciente lejos de las acciones de cuidado. **Descriptores:** Lepra; Diagnóstico; Enfermería.

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INTRODUCTION

Leprosy is a contagious disease caused by the bacterium Hansen’s bacillus, of slow evolution, that affects all the age groups, mainly the economically active adults. Due to the complexity of the changes and sequels caused by this bacillus, it is considered an important public health problem.¹

According to epidemiological data published by the World Health Organization (WHO), among the priority countries, India has 133.717 cases (greater number), whilst Brazil has 37.610, which puts it as the second country in quantity of cases. Of the 40.474 new cases in the Americas, 93% are cases notified in Brazil, although Asia has shown the highest detection rate, with 9,39 cases per 100.000 inhabitants, followed by the Americas, which show 4,58 cases per 100.000 inhabitants.²

In the State of Rio Grande do Norte/RN, leprosy reveals worrying indicators, particularly in the Upper West Region. According to the data presented by the Leprosy Control Program from the II Regional Public Health Unit (URSAP, as per its acronym in Portuguese), 42 leprosy cases were reported in this year in the municipalities of the II URSAP, distributed as follows: Serra do Mel (1); Campo Grande (1); Fernando Pedrosa (1); Angicos (2); Apodi (1); Assu (1) e Mossoró (35).³

Studies show the difficulty of local services in some Brazilian regions to accomplish the early diagnosis of leprosy cases, which contributes to an “epidemiological silence” by postponing the effective control and elimination of this disease.⁴

The treatment of leprosy patients in health services is adjusted to the integration of actions for preventing and controlling this disease in the Primary Health Care, a strategy that is used in Brazil. The process is based on principles of equity and accessibility: activities of diagnosis and treatment are linked to the community, and they are offered together with the other programs, available on all days of operation of the health units.⁵

We understand that leprosy requires constant therapy and monitoring. Nevertheless, it demands further attention from professionals, in such a way that they are sensitized to achieve better results in control actions, which is the big challenge for the diagnosis of the disease in its early stage.⁶

The confirmation of the diagnosis of leprosy is still very slow in most Brazilian states, since it takes approximately one and a half year to two years after the onset of signs

and symptoms of the disease. One should also emphasize the delay to seek care in health services, the lack of knowledge about the disease and the shortage of services as problems faced by patients. The lack of professionals with a sensitive clinical gaze to seek and confirm new cases also contributes to the delay in the diagnoses.⁷

In light of the foregoing, this study has the following objective:

- To analyze possible difficulties faced by leprosy patients to confirm the clinical diagnosis.

METHOD

This paper was developed from the Term Paper of the Bachelor Degree in Nursing << Leprosy: an analysis of possible diagnostic difficulties faced by the patient with the Hansen’s bacillus in Mossoró-RN >>, presented to the Faculty of Nursing Nova Esperança (FACENE, as per its acronym in Portuguese) Mossoró/RN, Brazil, 2013.

It is a descriptive study, with qualitative approach. The research was conducted in three basic health units: *Dr. Chico Porto, UBS - Dr. Chico Costa e UBS - Dr. Sinharinha Borges*, located in the municipality of Mossoró, in the State of Rio Grande do Norte (RN). Due to the fact that these units concentrate a significant number of confirmed cases of people with the Hansen’s bacillus according to epidemiological bulletin of leprosy.

The sample would be composed of 20 patients with the Hansen’s bacillus with confirmed diagnosis and undergoing treatment, who would be inserted in the areas embraced by the Basic Health Units (UBS, as per its acronym in Portuguese), but only 17 patients became able to be part of the sample according to the following inclusion criteria: the sick people with confirmed diagnosis, undergoing treatment, aged over 18 years. As for the exclusion criteria, they were: the patients under the age of 18 and with mental disorders. A form with questions related to diagnosis and characterization of participants was used as an instrument.

The data collection was performed during home visits, which had the help of a Community Health Agent (ACS, as per its acronym in Portuguese). Hence, the objective, the justification and the possible research risks were presented; then, the signature of the Free and Informed Consent Form (FICF) was required, thereby following the guidelines of the Resolution nº 466 of the National Health Council, which involves research with human beings, as well as the

Resolution nº 311/07, which deals with the Code of Ethics for Nursing Professionals, document that contains information relating to the research ensuring the right of the participant, freedom of the individual to refuse to participate or withdraw its consent at any phase of the research, without any penalty and without damage to its care; warranty of secrecy that ensures the privacy of subjects with regard to the confidential data involved in the research.

The analysis was conducted through the technique of Content Analysis, in the modality of thematic analysis, exposed as follows: speech of the interviewees in the full version, impressions of the researcher and quotes of the authors. In order to ensure the secrecy of the patients with the Hansen's bacillus, the alias 'user' was applied, according to the following examples: user 1, user 2, user 3, user 4, user 5, user 6, user 7, user 8, user 9, user 10, user 11, user 12, user 13, user 14, user 15, user 16 and user 17. The research project was submitted to the Research Ethics Committee of the Faculty of Nursing Nova Esperança of Mossoró (FACENE), under the Protocol nº 14/13, CAAE: 12254113.3.0000.5179.

RESULTS AND DISCUSSION

With the objective of obtaining relevant information to the diagnosis of the disease, the research participants were asked both about the suspicion and the diagnosis, with the intention of analyzing if there was any difficulty.

When asking the interviewees with the question << How did you discover that you had the disease? >>, we could analyze whether the suspicion emerged from a health professional or through own knowledge about the disease or others. The responses of the participants were similar in most cases, with some variations between them.

I didn't realize the mark on my forehead, so I went to the Rafael Fernandes (Reference Hospital in Mossoró). (user1)

The doctor of the health station said it was a kind of pityriasis, I took medications, but the spots grew, I was sent for a specialist doctor of the reference of the city. (user2)

The doctor prescribed a cream to remove spots; later, I was sent to another doctor, who sent me to a specialist in the reference. (user3)

The nurse from the Emergency Care Unit saw the spot and guided me to show it to the doctor. (user4)

I took allergy medicines, but it didn't work at all. After a long time, the nurse of the

FHS sent me to the specialist of the reference. (user5)

The main strategy of the Brazilian Ministry of Health is the promotion of actions of diagnosis and treatment of leprosy in the primary care, in which teams of the Family Health Program (PSF, as per its acronym in Portuguese), Community Health Agents (ACS, as per its acronym in Portuguese) and all units of the Brazilian Unified Health System (known as SUS) start to gather a host network for the patient, thereby promoting the universal access to diagnosis and treatment.⁸

In the city of São José do Rio Preto (SP), we observed that the most demanded service by users in case of disease was the primary care (UBS), followed by hospital, pharmacy and private health services. Among the difficulties to start the treatment, according to the interviewed patients, the most cited was the delay in diagnosis.⁷

The prevention of leprosy is mainly held in the primary care, in which actions are performed with the objective of stimulating and promoting health education, early detection and disease prevention, cooperation of society, as well as the training of health professionals. The majority of the actions are developed in the health unit of primary care, but situations demanding the referral of the patient to Specialized Reference Units, belonging to the other levels of complexity of the SUS, might take place, thereby ensuring the comprehensiveness of care.⁹⁻¹⁰

When trying to control leprosy, the managers find several difficulties, such as the lack of knowledge on the part of professionals in the primary care, the problems of patients within their coverage area and the training of human resources in the different professional levels. Together with the clinical and epidemiological characteristics of the disease, these factors lead to the hidden prevalence in the community, which entails many cases that are detected only belatedly.¹¹

Moreover, the participants were asked with the following question << Who gave the diagnosis? >>, through which we sought to identify the professional that confirmed the diagnosis.

It was the doctor from a private clinic of this city. (user14)

The dermatologist was the one who diagnosed and sent me to a specialist in leprosy. (user2, user3; user6)

The nurse sent me to the specialist of the reference. (user5)

All the research participants were unanimous in their responses:

treatment and approach to patients with the Hansen's bacillus and their family members on the part of health professionals, thereby realizing the importance and the need for actions in health education coming from nurses, which involves actions ranging from health promotion and protection, prevention of damages, diagnosis, treatment, rehabilitation and maintenance of health, in the various stages of the process, until the healing.⁹

The diagnosis of leprosy is particularly done through the valorization of the main complaints of the people with the bacillus. The lack of full or partial sensitivity of cutaneous injuries is one of the most indicative causes of the disease. The great number of injuries, among other characteristics, suggests a delay in diagnosis. This delay is due to the lack of awareness of health professionals and the occurrence of wrong diagnosis, besides the absence of a qualified and active primary care network to diagnose leprosy.⁶

In most Brazilian states, the confirmation of the diagnosis of people with leprosy is still very slow, approximately one and a half year to two years after the onset of signs and symptoms typical of the illness, given the delay to seek care in health services, the lack of knowledge about the disease and the shortage of services, which are problems faced by these patients.⁷

The high prevalence of leprosy in Brazil has various contributing factors, the main ones are: the late diagnosis of the disease; lack of continuing education to health professionals; shortage of educational activities at the community and/or family level; poor knowledge of the population about the disease; deficiency of transport for active search; insufficient material for examinations and reduced health care coverage. These factors contribute to the diagnosis and treatment of disease in a negative way.¹⁵

The information and the knowledge with regard to leprosy, its signs and symptoms, help in the promotion of early diagnosis and of an adequate treatment, with good chances of healing. Thus, the patient will be considerably less prone to present physical disabilities or deformities provoked by this illness.¹⁶

When asked about the possibility of having faced some difficulty for the diagnosis, most of them responded 'not'. In order to analyze the topic in question, it was necessary to produce a form to extract relevant and complementary information from the research subjects. Although they have responded that they had no difficulty in relation to the

diagnosis, when analyzing the previous responses, such as time to diagnosis up to four years, other suspicions of diagnosis, other treatments, which were not reported as difficulties, are factors that might have interfered with the early diagnosis or treatment in some degree.

Due to the fact of being a continental country, Brazil presents changes in the distribution of the disease. In the Brazilian South, the disease already displays prevalence below one for every 10.000 inhabitants, but shows high incidence in the Legal Amazon and in the State of Mato Grosso do Sul. This is a result of various factors, among them, the difficulty of access from the population to health services, thereby leading to late diagnoses. Due to the delay in diagnosis and adequate treatment, the people with multibacillary leprosy are transmitting the disease.¹

The leprosy patients need to know their disease, signs and symptoms, in order to know how to treat it in an adequate form. The right to information is essential in the health-disease process, thereby contributing in the prevention of disabilities and deformities.¹⁷ Patients undergoing treatment in the municipality of São José do Rio Preto (SP) were asked about the difficulty for treatment, where most interviewees did not show problems, but those who found some difficulty reported the delay in diagnosis.¹¹

When faced with the problem related to the difficulty of diagnosis in the municipality of Ipatinga (MG), we found that the lack of training to deal with leprosy directly influences in the unpreparedness of the health professionals to pay attention to the diagnostic suspicion of the disease.¹²

Patients with the Hansen's bacillus reported in a study that physicians through which they were assessed had difficulty in confirming the diagnosis, thereby generating embarrassing situations, until the moment of finding a professional able to confirm the diagnosis.⁷ The Information System for Notifiable Damages (SINAN, as per its acronym in Portuguese), founded by the Ministry of Health, in 1993, with the intention of monitoring the diseases in an epidemiological way, should assist in monitoring the goal of eliminating leprosy as a public health problem. Nevertheless, the health professionals are faced with incoherencies that hinder the planning of control actions in some degree, whether in the municipality, state or country.¹¹

Other countries have achieved the goal. Brazil has human resources and the

medication is free, that is to say, there is a lack of determination to definitively solve this question, because our country has all the conditions to eliminate leprosy as a public health problem.⁹

The need for satisfactory training for professionals who act in the primary health care is noticeable, because many had only basic knowledge in relation to leprosy, which hampers the diagnosis of new cases, treatment, rehabilitation of the disease and, even, the prevention of eventual disabilities and deformities.¹⁵

CONCLUSION

With the present study, the research objective was achieved, since it was possible to identify factors that have influenced in the confirmation of the diagnosis in a negative way. Commonly, the suspicion did not emerge from a health professional. When it emerged from a professional, it guided the patient to seek the secondary and/or tertiary care, where the diagnoses were given by the physician of the reference.

We found that the fact of referring a patient to the secondary and/or tertiary care is a common practice in the municipality. This attitude on the part of professionals contributes to the diagnosis of leprosy in a negative way. This further highlights the difficulty or the lack of sensitivity of the professionals in the entrance gate to health care, where the patients should be diagnosed and treated, and referred to the reference in specific situations of health problems.

We hope that the study might serve as a guiding parameter for changes in the municipal management, with sights to promote changes in health care models and a management that should give support to the physical structure of care, in such a way that the qualification in the work against this pathology becomes a compromise.

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